

## Why are you requesting a blood sample?

Analysis of blood samples can tell researchers a lot about **the health of the population**. Collecting blood samples now will give researchers really helpful information about different aspects of people's health. For those people who took part earlier in Understanding Society when we previously collected blood samples, we will be able to look at changes in health since then.

## Are there any health or medical reasons why I should not give a blood sample?

We advise people with certain conditions do not take a blood sample. These are:

- Participants who are **pregnant**
- Participants with **clotting** or **bleeding disorders**
- Participants who are currently on **anti-coagulant medication** (e.g. Warfarin therapy)
- Women who have had a **recent mastectomy** and there is swelling of the arm
- Participants who are on **renal dialysis**
- Participants who are **HIV, Hepatitis B** or **Hepatitis C positive**

## What is involved in giving a blood sample?

If you give us permission in your interview, the blood testing laboratory, Thruva will send you a **blood sample collection kit** through the post. The kit is small enough to fit through the letterbox.

If more than one person in the household has agreed to have a kit sent, please **make sure that you are using the kit that is addressed to you**. The only way we can match the sample to the person is the **ID barcode** which is on the kit. If there is a mix-up within a household, and you send back the sample that has someone else's barcode, then we will not be able to analyse the blood.

When you receive the kit, please open it, and read all the instructions carefully.

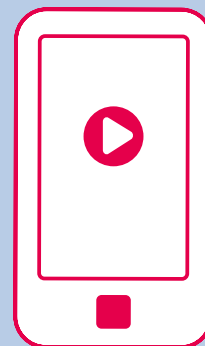
You will need to prick your finger and collect the drops of blood into two small tubes. A short video showing you what's in the kit, and how to use it can be found at <https://vimeo.com/790753028/34d7543734>

**You will find it helpful if you watch the video before you start.**

When you've taken the sample, you need to return the tube containing the sample in the pre-paid envelope provided in the kit. When the sample is received by **Thruva**, they will test your blood. We will send the result to you if you asked us to do this.

The results are not diagnostic, they are for research purposes only. If you have any concerns about your health, you should contact your GP as usual.

**To say thank you for collecting the sample we will send you a £10 voucher after the sample is returned to us.**



## Where can I find out more about how my information is used?

You can find out more about how we use your information at [www.understandingsociety.ac.uk/projects/health/privacy](http://www.understandingsociety.ac.uk/projects/health/privacy)

## What if I change my mind during the study?

Your participation is entirely voluntary. You don't have to do any part of the study that you don't want to. You have the right to withdraw from the study at any time – you do not need to give a reason. You can withdraw your consent to store your blood at any time, without giving a reason, by asking us in writing for your blood to be removed from storage and destroyed.

## What if I have concerns about the way the study was carried out?

Please contact Michaela Benzeval, the Director of Understanding Society

☎ 01206 873983 ✉ [mbenzeval@essex.ac.uk](mailto:mbenzeval@essex.ac.uk)

Paul Clarke, the Research Director of ISER

☎ 01206 873760 ✉ [pclarke@essex.ac.uk](mailto:pclarke@essex.ac.uk)

Mantelena Sotiriadou, the Research Governance and Planning Manager at the University of Essex

☎ 01206 876320 ✉ [ms21994@essex.ac.uk](mailto:ms21994@essex.ac.uk)

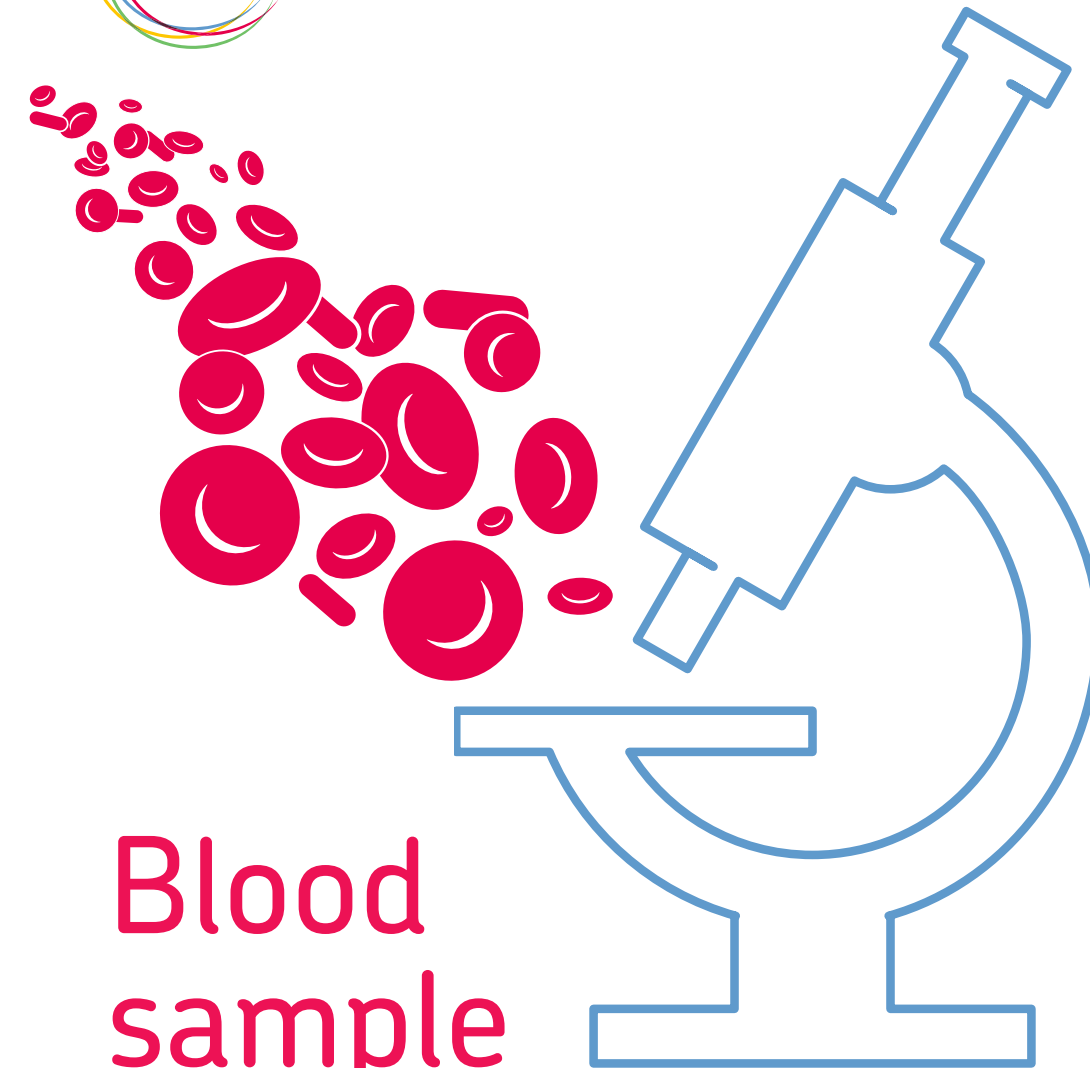
## Any questions?

For more information on the blood sample collection go to [www.understandingsociety.ac.uk/projects/health/blood](http://www.understandingsociety.ac.uk/projects/health/blood)

If you have changed your mind about the analysis that we do with the blood, or receiving your results, please contact us. If you would like to contact us at any point you can email or speak to one of us using the contact details below:

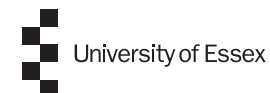
☎ 0800 252 853 ✉ [contact@understandingsociety.ac.uk](mailto:contact@understandingsociety.ac.uk)

If you are interviewed face-to-face, the interviewer will try to answer any questions you may have.



# Blood sample collection

Information for participants



## What will happen to the blood sample I provide?

We would like to study your blood samples for certain elements which have been shown to affect health by asking you to give a finger-prick blood sample. Anonymised data from the blood analysis will be made available to trusted researchers through the UK Data Service and other secure data repositories.

If you give us permission, we would also like to take a sample of DNA from your blood sample to carry out genetic tests. The genetics data will be made available to trusted researchers for analysis. Any analysis will have to be approved by a data access committee. The data will not be used for paternity testing, life insurance, or mortgage

applications, nor will any findings be fed back to you. You can give us permission to analyse your blood, but not take a DNA sample if you wish.

After studying your blood sample, if you give consent, we would like to store any remaining blood at a secure facility licensed under the Human Tissues Act and make it available for future research. Your blood will be available to trusted researchers for analysis. Any blood analysis will have to be approved by an independent committee. The stored blood samples will not be tested for the HIV virus, and will not be available for commercial purposes. Any findings from your sample will not be fed back to you.

## What analyses will be conducted on blood samples?

Your blood samples will be analysed for

### **Total cholesterol, Triglycerides:**

'Fat in the blood' associated with heart disease.

**HDL cholesterol:** 'Good cholesterol' in your blood.

**Creatinine:** How well your kidneys are working

**Liver function tests:** How well your liver is working.

**The vitamin D** in your blood, which is important for bone health.

### **Ferritin:**

The levels of iron in your blood, a measure of anaemia.

**HbA1c (glycated haemoglobin):** The sugar in your blood, a test for diabetes.

### **C-Reactive Protein:**

Inflammation, either due to an injury, or infection, or in response to stress.

### **Testosterone,**

### **Dehydroepiandrosterone:**

Hormones in your body, associated with stress, building muscle and ageing.

### **Steroid Hormone Binding**

**Globulin:** Protein that carries steroids, such as testosterone, in the blood and around the body.

Blood samples will be analysed in the UK, Europe or other countries with the equivalent data protection under the General Data Protection Regulation (GDPR).

Your DNA will be analysed by an accredited laboratory to identify thousands of genes in your blood. Variations in DNA result in slightly different versions of genes in different people - these genes are responsible for influencing biological processes and how your body works. Combining this genetic data with information about your environment, lifestyle and health allows researchers to investigate the complex interaction of people's health and circumstances. Over time how genes function can be changed, either naturally or by our environment. One measurement of this is known as 'methylation'. We will also measure this so researchers can explore if and how this puts people at increased risk of health problems.



## When will I get my feedback?

If you have requested feedback, we will send you it within a few weeks of you returning your blood sample in the post. We will provide feedback of your cholesterol and Hba1c (blood sugar level) results.

## What if there is a concern with my blood results?

If an immediate and serious concern is raised about your results, the Survey Doctor may contact you if they feel it poses a very severe risk to your health, even if you did not ask for feedback. This is part of our professional duty of care.

## Who is carrying out the research study?

Researchers at the Institute for Social and Economic Research (ISER) at the University of Essex are running the study. Verian (formerly Kantar Public) and National Centre for Social Research (NatCen) will be working with us to conduct fieldwork. Funding has been provided for the study by the Economic and Social Research Council (ESRC).

If you request a kit, Verian will send your address to the blood testing company Thriva who in turn will send you the kit with a barcode. When you return the sample, it goes back to Thriva.

More information about **Thriva** can be found on their website <https://thriva.co/> Genetic measurements from DNA in blood will be carried out by an accredited laboratory. Blood will be stored at a secure facility licensed under the Human Tissues Act.

## Do I have to take part?

No. Whether you take part in the study is entirely up to you. Even if you do decide

to take part, you can change your mind at any time without giving a reason. You can withdraw your consent to store your blood at any time, without giving a reason, by asking us in writing for your blood to be removed from storage and destroyed.

## What are the benefits of taking part?

Taking part will help us learn more about health and well-being, and will contribute to research on the health of the population.

## What are the risks of taking part?

Your finger may be a bit sore from the finger prick needed to produce blood drops. As you would with any small cut, the area should be kept clean to avoid infection. However, the process and products in the kit are used routinely in a wide range of healthcare applications, including measurement of blood glucose levels in the management of diabetes. The equipment is **sterile** and following the instructions provided in the kit will **minimise risk of infection** (such as cleaning the area before and after). In the unlikely event you injure yourself or feel unwell, please seek medical attention. Use the NHS 111 online service. If you do not have internet access, call NHS 111. For a medical emergency dial 999.

## Has the study been reviewed and approved by an Ethics Committee?

Yes. Before any research like this can be done it is looked at carefully by an Ethics Committee. In this case, the study has been approved by the NHS Health Research Authority, East of England - Essex Research Ethics Committee, reference: 22/EE/0260.

## How will you use information about me?

We will need to use information from you for this study.

This information will include your name and contact details. Verian and NatCen, our fieldwork partners, will use your name and contact details to carry out the study. If you take part in the blood sample collection, Thriva, the lab carrying out the analysis, will use your contact details and your date of birth and sex so that they can send you a collection kit and analyse your blood sample. Verian will send you the results of your blood analysis, if you wish to receive these.

If you agree to have your blood stored for future research, your name and address will not be attached to the sample - your sample will remain confidential. Before being used in future research, some of the information we have collected in this survey (but not any details which would identify you) may be attached to the sample.

We will keep all information about you **safe** and **secure**. The results of the study will never include any names or addresses. The information collected is used for research purposes only and will be dealt with according to the principles of the Data Protection Act and General Data Protection Regulation (GDPR).

Once we have finished the study, the anonymised data are made available from the UK Data Archive, the European Genome-Phenome Archive, other secure data repositories, or by the Study team to trusted researchers. All research reports are written in a way that no-one can work out that you took part in the study.

## What are my choices about how my information and blood sample are used?

**Your participation is entirely voluntary.** You don't have to do any part of the study that you don't want to. You can stop being part of the study at any time, without giving a reason. In the unlikely event that you lose capacity, we would withdraw you from the study. You, or a representative on your behalf, can request that your information is removed. We can remove any information that you have given us which has not yet been deposited with the UK Data Archive and other secure data repositories, but we are not able to remove data which has already been made available to researchers. Any personal information held by us, such as your contact details can be removed at any time.

If you withdraw your consent to store your blood for future research, we will destroy your blood sample. However, where your blood sample has already been analysed and the research findings are in the public domain, we are not able to remove your blood results from the data.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to change the data we hold about you. If you wish to see the data we hold about you, you can make a data subject access request.

